Treatment Summary and Survivorship Care Plans: Letting this tool work for you!

Leslie Heron, RN, BSN, MN, APRN, FNP-BC

Moving Beyond Cancer to Wellness
June 6, 2015
Objectives

• Learn what a Treatment Summary and Survivorship Care Plan is
• Understand why this document is recommended for cancer survivors
• Hear some ways this document can help cancer survivors in clinical situations
• Learn how to access a Treatment Summary and Survivorship Care Plan
Treatment Summary Goal

• Increase survivors own knowledge of their diagnosis and the treatment they have received

• Assist transition back to, and to inform, primary care and other healthcare providers
Survivorship Care Plan Goal

- Increase knowledge of potential consequences of cancer treatments
- Recommend health screenings and surveillance
- Promote a healthy lifestyle and illness prevention
Where Did This Idea Come From?

• There are more people surviving cancer
  – Screening tests for cancer are better
  – Earlier screening is happening
  – More effective treatments are available

• Cancer survivors are living longer
  – Both childhood and adult survivors are living long lives after treatment has been completed

• Survivors are speaking up
Late and Long Term Effects May Include...

Medical Problems:
- Cardiovascular disease and cardiac failure
- Fatigue
- Pain
- Osteoporosis / osteopenia
- Hypothyroidism
- Premature menopause
- Pulmonary function
- Lymphedema
- Urinary incontinence
- Infertility
- Neurologic problems (balance, neuropathy, memory)
- GI (bowels, bloating, acid reflux)
- Dental impairments
- Recurrence
- Increased risk of 2\textsuperscript{nd} cancers
- Accelerated aging

Emotional and Functional Concerns:
- Memory loss
- Restricted social and physical activities
- Fear of recurrence/living with uncertainty
- Muscle and joint stiffness, weakness, cramps or pain
- Sexual dysfunction
- Intimacy/relationship issues
- Distress and worry
- Job loss/Job lock
- Role changes at home
- School concerns
- Insurance problems
- Financial concern or crisis
- Sleep disorders
- Cognitive processing disruption
IOM Report Identified Survivorship Needs:

1. Every survivor should receive a treatment summary and care plan at the end of treatment.

2. Prevention, surveillance, and detection of new and recurrent cancers.


4. Coordination between specialists and primary care providers to ensure that survivor health needs are met.
Inclusion of Survivorship in COC Accreditation Standards

Cancer Program Standards 2012: Ensuring Patient-Centered Care

Phase in for 2015.

STANDARD 3.3 Survivorship Care Plan

The cancer committee develops and implements a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment.

The process is monitored, evaluated, and presented at least annually to the cancer committee and documented in minutes.

DEFINITION AND REQUIREMENTS

The IOM and National Research Council 2005 report, From Cancer Patient to Cancer Survivor: Lost in Transition, recommends that patients with cancer who are completing the first of course treatment be “provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.” The recommendation suggested that these plans would help cancer survivors who may otherwise get “lost” in the transitions from the care they received during treatment through the phases of their life or stages of their disease course. The purpose of this standard is to have cancer programs develop and implement a process to monitor the dissemination of a survivorship care plan as a part of the standard care of patients with cancer. The process is implemented, monitored, evaluated, and presented annually to the cancer committee. The presentation is documented in minutes.

PROCESS REQUIREMENTS

(a) A survivorship care plan is prepared by the principal provider(s) who coordinated the oncology treatment for the patient with input from the patient’s other care providers.

(b) The survivorship care plan is given to the patient on completion of treatment.

SPECIFICATIONS BY CATEGORY

All programs fulfill the standard as written.

DOCUMENTATION

The program completes the SAR.

During the on-site visit, the surveyor will discuss with the cancer committee the methods implemented to create and disseminate a survivorship care plan.

MONITORING COMPLIANCE

Rating

(1) Compliance: The program fulfills the following criteria:

1. The cancer committee has developed a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment.

2. Each year, the process is implemented, monitored, evaluated, and presented to the cancer committee.

(5) Noncompliance: The program does not fulfill 1 or more of the following criteria:

1. The cancer committee has developed a process to disseminate a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment.

2. Each year, the process is implemented, monitored, evaluated, and presented to the cancer committee.
(a) A survivorship care plan is prepared by the principal provider(s) who coordinated the oncology treatment for the patient with input for the patient's other care providers.

(b) The survivorship care plan is given to the patient on completion of treatment.

(c) The written or electronic survivorship care plan contains a record of care received, important disease characteristics, and a follow-up care plan incorporating available and recognized evidence-based standards of care, when available.
So, What Does a Treatment Summary and Care Plan Look Like??
# Seattle Cancer Care Alliance
## Cancer Treatment Summary and Survivorship Care Plan

### Test/Test

<table>
<thead>
<tr>
<th>Dx</th>
<th>Cancer Diagnosis</th>
<th>Values with * are estimated</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Unknown</td>
<td>Date of Diagnosis 5/17/1998 [Age 51]</td>
</tr>
</tbody>
</table>

#### Laterality
No data reported

#### Subtype/Staging
- **Histopathologic Subtype**: No data reported
- **Stage**: No data reported
- **Size**: No data reported
- **Histologic Grade**: No data reported
- **Regional Lymph Nodes**: No data reported
- **Metastases**: No data reported

#### Staging or Other Comments
No data reported

### Significant Past Medical History:
- 6/1/2005 - Cataracts
- 2011 - Pacemaker
- 1/5/1998 - Anemia (unrelated to cancer therapy)

### Family History:
No data reported

### Treatment Facility:
Seattle Cancer Care Alliance
University of Washington Medical Center

### Cancer Treatment

#### Surgery

<table>
<thead>
<tr>
<th>Dx</th>
<th>Procedure</th>
<th>Site</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No data reported</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Systemic Therapy

<table>
<thead>
<tr>
<th>Dx</th>
<th>Agent</th>
<th>Dose</th>
<th>Start</th>
<th>Stop</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Paclitaxel (Abraxane, Taxol)</td>
<td>5800.00 mg/m2 [Total] - IV</td>
<td>2/12/2001</td>
<td>2/28/2001</td>
</tr>
</tbody>
</table>

#### Radiation Therapy

<table>
<thead>
<tr>
<th>Dx</th>
<th>Radiation Type</th>
<th>Site</th>
<th>Dose</th>
<th>Start</th>
<th>Stop</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>External Beam (conventional)</td>
<td></td>
<td>2590 centigray (cGy)</td>
<td>4/1/2001</td>
<td>4/17/2001</td>
</tr>
<tr>
<td>Long Term Effects and Follow Up Care</td>
<td>Recommendation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>----------------</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Oncology Care</strong></td>
<td>Your oncologist will determine how often and for how long, you should be seen based on your specific needs, including the need for blood tests and radiology exams. Most patients diagnosed with cancer continue to be followed by their oncologist for at least 5 years from diagnosis.</td>
<td></td>
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</tr>
<tr>
<td><strong>Eye/Vision</strong></td>
<td>Radiation, steroids, and other medications increase the risk of cataracts, dry eyes, and changes in the blood vessels in your eyes. Annual eye exams are recommended. If you experience blurred vision, light sensitivity, difficulty with reading or night vision, or sudden vision changes, more urgent evaluation may be needed.</td>
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</tr>
<tr>
<td><strong>Hearing</strong></td>
<td>Treatment of your cancer with certain chemotherapy agents, head/neck radiation, and other drugs used during your treatment may affect your hearing. Audiology evaluation is recommended if you are noticing changes in your hearing. Symptoms can include ringing in your ears, hearing loss, or changes in balance.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Oral/Dental</strong></td>
<td>Chemotherapy and/or radiation may increase the risk for cavities, tooth and mouth sensitivity, and oral cancer. Twice yearly dental exams and cleanings are recommended. Things to watch for include dry mouth, change in sense of taste, gum irritation or bleeding, tooth or jaw pain, and delayed healing following dental work.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Speech/Swallowing</strong></td>
<td>Radiation and surgery to your head and neck can cause changes in your speech, dry mouth, and difficulty swallowing. Speech or occupational therapists can help with rehabilitation of these problems. New or sudden changes in speech or swallowing need to be addressed more urgently with a medical provider.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Thyroid</strong></td>
<td>Surgery and/or radiation to the thyroid can impact your thyroid gland. Blood tests for thyroid function and physical exam of the neck are recommended annually. Changes in metabolism such as unexpected weight gain or loss, irregular heart rate, fatigue, mood changes, and bowel or menstrual changes require evaluation by your provider. If thyroid function abnormalities are found, medication may be recommended and an endocrinology referral might be considered.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long Term Effects and Follow Up Care</td>
<td>Recommendation</td>
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<td>-------------------------------------</td>
<td>----------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiac (Heart) with high exposure</td>
<td>Heart problems can occur after certain chemotherapy drugs (anthracyclines) or after chest radiation depending on the doses you have received. An electrocardiogram (ECG), echocardiogram, and/or other cardiac studies may be recommended on a routine schedule based on your level of exposure. Annual evaluation of blood pressure, cholesterol, weight, blood sugar, carotid vessel and heart health is recommended. Be aware of your heart beating too fast (tachycardia), irregular heart rate (arrhythmias), shortness of breath or increased fatigue and report these to your health care provider. Please call 911 for sudden onset of chest pain, pressure or shortness of breath.</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wellness Topic</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart Health</td>
<td>Eat a low fat diet, get regular aerobic exercise, avoid smoking and maintain a healthy weight. Monitor blood pressure and cholesterol levels. Be aware of your family history and personal risks for diabetes, stroke, and heart disease.</td>
</tr>
<tr>
<td>Intimacy/Sexual Health</td>
<td>Intimacy can be hard to initiate after cancer treatments. Communicate with your partner and allow time for talking and re-learning about each other. Discuss what does and does not feel good now and plan time for intimacy. Vaginal lubricants, moisturizers or localized estrogen therapy may be helpful for dry or painful tissues. Consider the assistance of a counselor for intimacy issues and a woman’s health specialist for help with vaginal atrophy or other physical issues if needed.</td>
</tr>
<tr>
<td>Nutrition</td>
<td>Nutrition is critical to optimize health, improve fatigue and mental acuity, and reduce cancer risk. Eat a wide variety of fruits, vegetables and whole grains, stay well-hydrated, and limit fat, salt, and alcohol intake. A nutritionist can assist you in customizing dietary recommendations for your needs.</td>
</tr>
</tbody>
</table>
Now...
Let’s See How a Treatment Summary and Care Plan Can Work for YOU!
<table>
<thead>
<tr>
<th>Long Term Effects and Follow Up Care</th>
<th>Recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral/Dental</td>
<td>Chemotherapy and/or radiation may increase the risk for cavities, tooth and mouth sensitivity, and oral cancer. Twice yearly dental exams and cleanings are recommended. Things to watch for include dry mouth, change in sense of taste, gum irritation or bleeding, tooth or jaw pain, and delayed healing following dental work.</td>
</tr>
</tbody>
</table>

Mike’s dentist had been seeing him for a few years, and was surprised Mike had so many cavities and receding gums. Mike brushed, flossed, came in for dental visits regularly. What Mike’s dentist didn’t know was that Mike had chemotherapy and radiation for Hodgkin Lymphoma many years before.

Mike came in for a Survivorship Clinic visit and finally understood what was going on, and why!

When Mike brought his Treatment Summary and Care Plan to a dental visit, his dentist was able to come up with a better preventative plan for Mike.
June had breast cancer many years ago. She had done physical therapy for a few months after her surgery and radiation to get her range of motion and strength back. She never had a problem with lymphedema. Just last year, after she retired, she and her husband had the opportunity to travel.

June noted that her arm felt “heavy” and uncomfortable while they were traveling, and then her hand started swelling up a bit. Her rings were tight. What was going on?

She read back through her Survivorship Care Plan when they got home and took it in with her to a medical visit. Her nurse practitioner realized June had lymphedema! After all of these years! June went back to physical therapy, now uses a lymphedema sleeve and glove with travel, and is doing well and enjoying her retirement travel.
Karl was treated in his teens for cancer, and now is in his mid-40’s and has been healthy and well. He has put on a little weight and wanted to get back in shape, but found he was feeling more fatigued after exercise. He thought he should feel better after exercise. He did not have a primary care provider, but he’d heard about Survivorship Clinic.

After reviewing his Treatment Summary, Karl realized he had been treated with Doxorubicin. This chemotherapy may have put him at risk for heart problems, even years after treatment. He is scheduled to have an echocardiogram, and has gotten in to see a primary care provider for a physical exam and blood work.
Sandra had lymphoma 8 years ago, and she had been doing great. She got in for routine check-ups, had blood tests done yearly, and had routine mammograms. Then she started feeling tired, and noticed her hair was getting thinner. Then her fatigue got worse and her shoulders felt achy. She began to worry that her cancer may have come back!

When she went in to see her primary care provider, they looked over her Treatment Summary and Care Plan together. Sandra had both chemotherapy and chest radiation during treatment. Her doctor realized they had never checked her blood work for thyroid hormone levels with her yearly labs.

Sandra’s exam and tests all came back normal, except her thyroid labs. She was put on thyroid medication and is feeling great again.
One More Care Plan Benefit to Share...
<table>
<thead>
<tr>
<th>Test</th>
<th>Last Done</th>
<th>Frequency</th>
<th>Provider to Contact</th>
<th>Next Due</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survivorship</td>
<td>2011</td>
<td></td>
<td>LTFU</td>
<td>2016</td>
</tr>
<tr>
<td>Complete Physical Exam</td>
<td></td>
<td>Yearly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oncology Follow-up</td>
<td></td>
<td>As per Oncologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surveillance for Risk of Recurrence</td>
<td></td>
<td>Set by your Oncologist</td>
<td>Dr. Oncologist</td>
<td></td>
</tr>
<tr>
<td>Bone Density Test</td>
<td></td>
<td>Every 2-5 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Colonoscopy</td>
<td></td>
<td>Every 10 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Screening Labs</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Gynecological Exam</td>
<td></td>
<td>Yearly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pap Smear</td>
<td></td>
<td>Every 3 years</td>
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<tr>
<td>Mammogram</td>
<td></td>
<td>Yearly</td>
<td></td>
<td></td>
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<tr>
<td>Breast MRI</td>
<td></td>
<td>Yearly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skin Exam</td>
<td>1998</td>
<td>Yearly</td>
<td>Dr. PCP</td>
<td>2016</td>
</tr>
<tr>
<td>Cardiac Screening</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Vision Exam</td>
<td></td>
<td>Yearly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental Exam</td>
<td></td>
<td>Twice a year</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Immunizations</td>
<td></td>
<td>Yearly</td>
<td></td>
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</tbody>
</table>

**Contact/Resources**

Seattle Cancer Care Alliance (SCCA) Survivorship Clinic  
825 Eastlake Ave East Seattle, WA 98109  
survivor@seattlecca.org  
Phone: 206-288-1021 Fax: 206-667-1502  
http://www.seattlecca.org/survivorship
I know you are asking yourself...

“How Can I Get One of These Nifty Treatment Summary and Survivorship Care Plans?”
SCCA Survivorship Clinic
FHCRC Survivorship Program

K. Scott Baker, MD, Director
Karen Syrjala, PhD, Co-Director
Leslie Heron, ARNP
Debra Loacker, RN
Gabriella Emond, Admin Assistant
Emily Rajotte, Program Manager
Joli Bartell, Project Coordinator
Sheri Ballard, Research Assistant
Kelly Ambrose, Project Manager
Treatment Summary & Care Plan Templates

• LIVESTRONG™ Care Plan Powered by Penn Medicine’s OncoLink
  www.livestrongcareplan.org
  – Patient-oriented tool
  – Comprehensive individualized list of recommendations specific to primary cancer diagnosis & treatment received
    • evidence & consensus-based
    • IOM, COG, NCI, ASCO
Other Treatment Summary & Care Plan Resources

- Search Cancer Survivorship on the web
- ASCO
  - Provider oriented
  - www.asco.org
- Journey Forward
  - www.journeyforward.org
  - Providers & Patients
  - Collaborative effort
    - National Coalition for Cancer Survivorship
    - The UCLA Cancer Survivorship Center, Wellpoint, Inc., Genentech
Thank you!